

Quality of life and symptoms among older people living at home

Ylva Hellström PhD RNT

Lecturer, School of Health Science, Blekinge Institute of Technology, Karlskrona; and Department of Nursing, Unit for Caring Sciences, Lund University, Lund, Sweden

Gunnel Persson RNT

(retired) Department of Health Science, Kristianstad University, Kristianstad, Sweden

Ingalill R. Hallberg PhD RNT

Professor, Department of Nursing, Unit for Caring Sciences, Lund University, Lund; and The Vårdal Institute, The Swedish Institute For Health Sciences, Lund University, Lund, Sweden

Submitted for publication 10 March 2003

Accepted for publication 20 December 2003

Correspondence:

Ylva Hellström,
Department of Nursing,
Unit for Caring Sciences,
Lund University,
PO Box 157,
SE-221 00 Lund,
Sweden.
E-mail: ylva.hellstrom@omv.lu.se

HELLSTRÖM Y., PERSSON G. & HALLBERG I.R. (2004) *Journal of Advanced Nursing* 48(6), 584–593

Quality of life and symptoms among older people living at home

Aim. This paper reports a study comparing the socio-demographic data, quality of life (QoL) and symptoms of older people living at home with and without help.

Background. Despite growing numbers of older people worldwide, little is known about the differences between older people receiving help to live at home and those not receiving this, especially as regards QoL and symptoms. Not only symptoms but also dependency on others *per se* may reduce older people's QoL. From a nursing perspective, knowledge about such issues is important because the impact of symptoms may be reducible, even when diseases cannot be cured.

Method. A postal questionnaire was sent to an age-stratified random sample of 1866 people aged 75 years or over. Of the respondents ($n = 1248$) 448 received help and 793 did not.

Results. The group receiving help had a significantly higher age, more women, more people widowed and living alone, more children, a higher number of self-reported diseases and symptoms, greater inability to remain alone at home and lower QoL. Loneliness, depressed mood and abdominal pain were significantly related to low QoL in both groups. Living alone, not being able to remain alone at home without help, and fatigue were also predictive of low QoL among those receiving help, and number of diseases and sleep problems in those without.

Conclusion. Receiving help with daily living seems to be significantly related to low QoL and goes along with a high number of symptoms that need to be considered in nursing care. Through regular visits, systematic assessment and intervention, especially focusing on older people's symptoms, nurses may contribute to improved QoL for this section of the population.

Keywords: older people, help, quality of life, living at home, symptoms, nursing

Background

All over the world there is an increasing number of older people, particularly those over 80 (Kinsella & Velkoff 2001) and, although health has improved in most countries, there will be more demands on health care and especially on nursing care. This requires knowledge of how best to contribute to maintaining or improving quality of life (QoL), as cure may not be possible. The majority of people receive help to live at home rather than moving to in various types of institutions, nursing homes or similar (Frederiks *et al.* 1990, Fernández-Ballesteros 2002). For instance, in 2002 in Sweden 92% of people aged 65 years and above lived at home and about 8% received publicly-provided help at home, while about 19% of those aged 80 years and above received this (Statistics Sweden (SCB) 2002, National Swedish Board of Health & Welfare 2003). Even more had help from relatives (Hellström & Hallberg 2001). It seems that the number of older people having help at home will increase, and there is a lack of knowledge about their QoL, health and symptoms. This can be remedied in part by comparing those who have help with daily living and those who do not. Such comparisons can also provide valuable knowledge about what nursing care should focus on.

Having help from others for everyday needs may evoke feelings of insecurity and anxiety about the future and the availability of others who can help (Jacobsson *et al.* 2000, Ellefsen 2002), and it also implies dependency, at least in physical terms. Thus, not only health problems but also dependency on others *per se* may reduce older people's QoL. Studies of QoL among older people in general, and those living in various kinds of institutions or having help at home, have identified various factors that influence QoL, e.g. socio-demographic factors, level of help, variety of activities and social and environmental factors (Lawton *et al.* 1995, Lindgren *et al.* 1998, Newsom & Schulz 1998, Al-Windi *et al.* 1999). No studies have been found which explore those living at home and receiving help in comparison with those not receiving help. Such knowledge could guide nursing assessments and interventions. It might also give an understanding of what the shift from being able to live without help to becoming dependent on others entails in terms of QoL, functional health status and symptoms.

The WHO definition of QoL is that it is a subjective evaluation embedded in a specific cultural, social and environmental context (WHOQOL 1998). It can be divided into overall/general QoL and health-related quality of life (HRQoL), and is often stated to be a multidimensional phenomenon (Browne *et al.* 1994). According to Lawton (1991), QoL consists of four main areas: objective environ-

ment, behavioural competence (including health), perceived QoL, and psychological well-being (including life satisfaction). Browne *et al.* (1994) found in their study of healthy older people (65–90 years of age) that older elders reported high levels of life satisfaction, psychological well-being and subjective well-being as compared with younger old people. Further, Browne *et al.* (1994) stated that each individual has a specific conceptualisation of what the health domain means for their QoL. Philip (1996) suggested that the most important aspect of care for older people should be to increase or preserve QoL, and therefore more knowledge about what contributes to QoL is needed.

Living longer in most cases also means having more symptoms and diseases, most of which seem to cause distress in daily living (Campbell *et al.* 1994, Grimby & Svanborg 1997, Melzer *et al.* 1999). From a nursing perspective such knowledge is important, because the impact of symptoms may be able to be reduced even when diseases cannot be cured. The relationship between symptoms, diseases and activities of daily living (ADL) is not fully understood. However, a longitudinal study over 6 years in the USA (Penninx *et al.* 1999) among 6247 people aged 65 years and above showed that depression in those who were initially not disabled significantly increased the risk of ADL dependence and mobility disability. Steen *et al.* (2001) found that, among people aged 85 years ($n = 332$) and 95 years ($n = 63$), there were differences in cognitive functioning, mobility and tiredness among ADL-dependent as compared with ADL-independent people. Melzer *et al.* (1999) found, among 10,377 people aged 65 years and above in the UK, that more than 80% of older physically disabled people needed help, as Jorm *et al.* (1993) had previously found in 1993 among people aged 70 years and above living in Australia. Grimby and Svanborg (1997), in a Swedish longitudinal study with older people aged 76, found that diseases had an impact on HRQoL. An interview study with people aged 85 years and over who were living at home in London showed that health status is a greater predictor of emotional well-being (Bowling & Browne 1991) than social network. Newsom & Schulz (1996), however, found among people aged 65 and over in the USA ($n = 4,734$, average age 72.8) that lower social support was an important reason for decreased life satisfaction. Thus, understanding so far of how QoL is influenced by various factors such as disease, self-rated symptoms and social network among older people is far from clear, especially in the oldest old (85+) group because of their low numbers in most studies.

Understanding the lives of older people, especially those receiving help with daily living, is important for future health care because their whole life situation influences the content

of their home care. Home care/help refers to all kinds of help at home needed for health problems and includes help with IADL (washing, shopping) or personal care. In Sweden, older people in general live at home in a private house or a flat. When they cannot do so any longer the municipalities have a responsibility to care for them in special accommodation (nursing homes, assisted living or similar). The trend in most countries seems to be in the direction of increasing numbers of people receiving help at home. In 1998 in Sweden 21% of older people aged 80 and over lived in special accommodation, while the figure was about 19% in 2002 (National Swedish Board of Health & Welfare 2000, 2003). The current policy with regard to care of older people in Sweden, as in many other countries, is to enable them to remain at home as long as possible (Swedish Institute 1999, Criddle & Flinker 2001), which certainly involves high quality nursing care. This calls for more knowledge about these people's life situations and what to look out for to improve their QoL.

The study

Aim

The aim of this study was to compare people aged 75 years and over, living at home and receiving help with daily living, with those without such help, with regard to socio-demographic data, self-reported illness, health problems and QoL.

Design

A cross-sectional survey design was used.

Participants

An age-stratified randomised sample of 1866 adults (response rate 67% $n = 1248$), 75 years or older, was selected in 1995 in a southern Swedish municipality with approximately 70,000 inhabitants, of whom 8.9% were 75 or above ($n = 6,225$; 38% men) and living at home. Thirty per cent were randomized from those aged 75–79, 80–84, 85–89, 90–94 and >95 years to make sure that enough very old people were included. The two age groups 90–94 and >95 were combined to form one group in the analysis because the number of respondents in the two groups was small.

Questionnaire

A postal questionnaire covering sex, age, number of children, living conditions, civil status, cohabitation, and helping another person was sent to respondents (Table 1). The

Table 1 Characteristics of respondents with and without help

	With help ($n = 448$)	Without help ($n = 793$)	<i>P</i> value
Age			
Mean (SD)	84.2 (5.15)	80.3 (3.72)	<0.0005
Gender (%)			
Female	65.9	59.4	<0.024
Living conditions (%)			
Countryside	15.1	12.1	NS
Village	22.8	24.5	
City	62.1	63.3	
Civil status (%)			
Married	34.1	51.2	<0.0005
Widowed	53.5	38.0	
Single	8.8	6.8	
Divorced	3.6	4.1	
Children, mean (SD)	2.3 (1.69)	2.0 (1.57)	<0.015
Cohabitation (%)			
Alone	62.4	48.3	<0.0005
With husband/wife	31.5	49.9	
With children	3.6	0.9	
With another person	2.5	0.9	
Able to be alone at home (%)			
All the time	31.5	90.9	<0.0005
From 1 to 7 days	28.3	2.1	
From 2 to 23 hours	26.1	0.9	
Cannot be alone at all	6.5	0.5	
Helping another relative or friend (%)			
Every day	6.8	5.7	NS
Sometimes	3.0	5.8	
Never	90.2	88.5	

Internal missing varied between 4 and 17. Missing in 'Able to be alone at home' were 34 (7.6%) cases among those receiving help and 44 (5.5%) cases among those without help. Missing in 'Helping another relative or friend' were 23 cases among those receiving help and 70 cases among those without any help.

NS, not significant.

questionnaire also covered symptoms, self-reported diseases and QoL (Figure 1, Tables 2 and 3). In addition, questions were asked about ability to be alone at home without someone available to help with health problems or personal ADLs. The response alternatives were given in number of hours that the person could remain alone. Questions were also asked about whether, because of reduced health, the person needed help with instrumental ADLs (e.g. shopping, meal preparation and housekeeping) and personal ADLs (e.g. bathing, dressing and feeding). The eight QoL questions were selected from a questionnaire based on the Life quality Gerontological Centre scale, Lund (LGC) (Nordbeck 1996). This has 49 items measuring global QoL and is based on the Life Satisfaction Index A (LSIA) (Neugarten *et al.* 1961), Philadelphia Geriatric Centre Morale Scale (Lawton 1975)

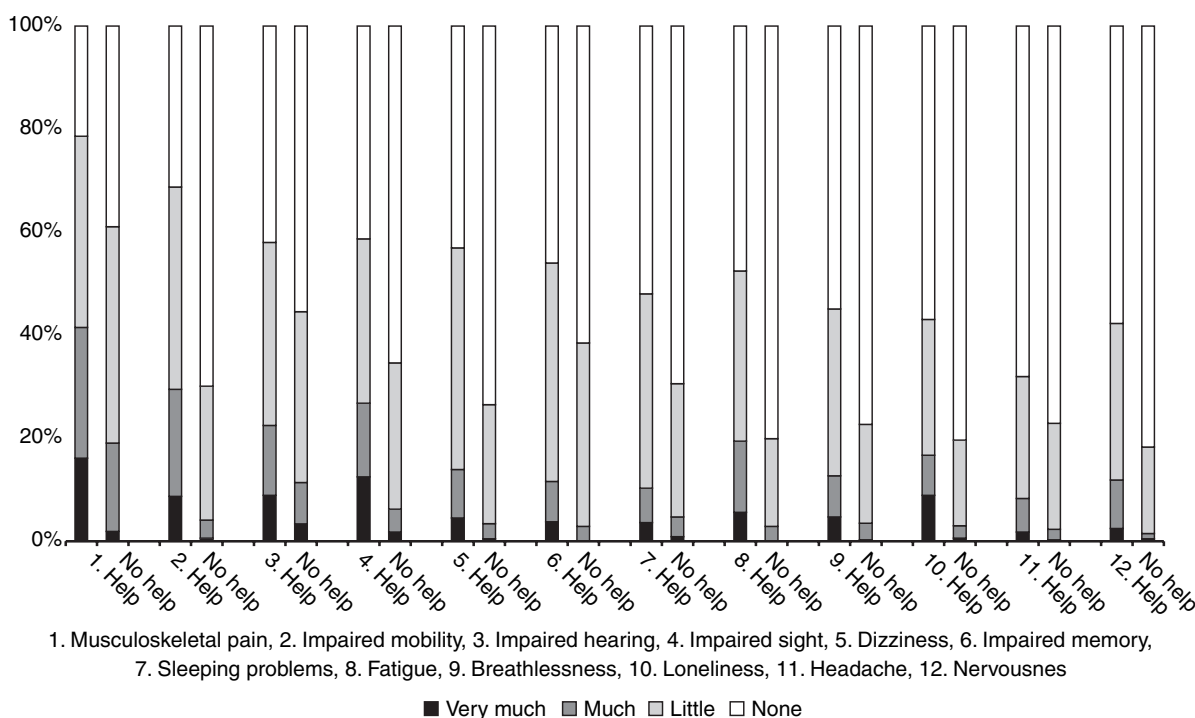


Figure 1 The most frequent complaints (in per cent) reported to be present during the last 3 months among older respondents receiving help and those without any help. Significant (P -value ≤ 0.0005) differences between the two groups in all variables presented.

and Life Quality Scale (Rubenowitz 1980). The LGC has previously been used among older people (Elmståhl *et al.* 1996, Nordbeck 1996, Hagberg *et al.* 2002).

Data collection

Respondents were asked to obtain help from relatives, friends, their home help or district health service if they were unable to fill in the questionnaire by themselves, and to indicate who helped them. One reminder was sent. Those whose questionnaires were returned marked 'Address unknown', or who had moved to institutions or had died, were randomly replaced by others from the same age group.

Ethical considerations

The Lund University Ethics Committee, LU 307-95, approved the project. An explanatory letter was sent with the questionnaire, and return of a completed questionnaire was taken as consent to participate.

Data analysis

A comparison between older people receiving help ($n = 448$) and those without help ($n = 793$) was made with regard to

QoL, demographic data, diseases and symptoms. Respondents who answered that, because of decreased health, they had help 'Several times a week', 'Once a week' or 'Yes, but not every week' were defined as receiving help ($n = 448$). Those who answered, 'No, I do not have any help or care' were defined as without help ($n = 793$).

The chi-square test was used to test for differences between the two groups for nominal data such as gender, living conditions, civil status, cohabitation, and types of symptoms and diseases. The Student's t -test was used to test for difference regarding age. Differences in variables such as 'able to be alone at home by themselves', 'helping another relative or friend', QoL questions, number of children, number of diseases and number of symptoms were tested using the Mann-Whitney U -test. The chi-square test was also used to test for differences between genders within each group (receiving help or without help) with regard to living conditions, civil status and cohabitation. The Mann-Whitney U -test was used to test for difference between gender within each group regarding QoL questions, number of children, number of diseases and number of symptoms. A new variable, 'Quality of Life', was constructed for statistical analysis purposes by adding the responses to each question about QoL. The scores on the added QoL questions could range from 8 to 28, with a low score indicating low QoL.

Table 2 Frequency (%) of self-reported diseases among those receiving help and those without any help

Diseases	With help (<i>n</i> = 448) %	Without help (<i>n</i> = 793) %	<i>P</i> value
Musculoskeletal disease	46.2	25.1	< 0.0005
Other circulatory disease	38.2	19.9	< 0.0005
Eye disease	35.0	20.1	< 0.0005
Hypertension	22.5	24.1	NS
Heart attack	20.1	11.6	< 0.0005
Disease of the joints/arthritis	14.1	5.8	< 0.0005
Diabetes mellitus	13.2	7.4	< 0.001
Bronchitis/emphysema/ Asthma/other respiratory disease	12.5	7.2	< 0.002
Urogenital disease	11.8	5.8	< 0.0005
Infections	11.2	4.3	< 0.0005
Hip fracture	11.2	6.8	< 0.008
Ear disease	9.6	5.9	< 0.02
Rheumatic disease	9.2	4.8	< 0.003
Gastrointestinal disease	8.9	5.2	< 0.01
Dermatosis	8.3	4.4	< 0.005
Metabolic disease	7.6	4.2	< 0.01
Other neuropathy disease	7.4	2.6	< 0.0005
Cerebrovascular disease	6.7	0.9	< 0.0005
Other psychiatric disease	6.7	0.9	< 0.0005
Hepatitis and biliary disease	4.5	2.1	< 0.02
Tumour	4.2	1.4	< 0.002
Blood/haematological disease	3.8	1.6	< 0.02
Multiple sclerosis/ Parkinson's disease	3.8	0.8	< 0.0005
Dementia	5.1	0.3	< 0.0005
Congenital defect disease	1.1	0.5	NS
Number of diseases per person = median (q1/q3)	3 (2/5)	1 (1/3)	< 0.0005

Internal missing = 7 cases.

Chi-squared test differences represented in diseases and Mann-Whitney *U*-test in the number of diseases between the two groups.

Cronbach's alpha was used to assess internal consistency of the summed QoL measure. Multiple linear regression analyses were used to find variables explaining QoL (dependent variable). The independent variables were age, gender, number of self-reported diseases, number of symptoms, number of children, living condition, civil status, living alone or not, the ability to stay alone at home or not and those symptoms (*n* = 14) that were correlated to QoL with a high correlation coefficient of > 0.25 (Spearman's rank-order) (Cohen & Manion 1989). Dummy variables were constructed for living condition using 'city' as a reference and for civil status using 'married' as a reference. SPSS for Windows 95 and 98 software package, version number 10.1 and 11.0 was used.

Table 3 The respondents' present quality of life

	With help (<i>n</i> = 448) %	Without help (<i>n</i> = 793) %	<i>P</i> value
How do you feel at present? (a,c)			< 0.0005
Very good/good	68.5	92.2	
Bad/very bad	31.5	7.8	
How do you feel about your life today? (a,c)			< 0.0005
Very good/good	74.4	93.8	
Bad/very bad	25.6	6.2	
Do you often think life could be less monotonous? (a,d)			< 0.0005
Seldom/never	63.5	85.3	
Very often/often	36.5	14.7	
Do you often feel depressed because every day is the same? (a,c)			< 0.0005
Seldom/never	66.9	88.8	
Very often/often	33.1	11.2	
I am just as happy and satisfied as when I was younger (a,d)			< 0.0005
No	45.5	21.0	
Do not know/doubtful	29.3	28.2	
Yes	25.2	50.8	
My life could be more eventful than it is now (b,e)			< 0.0005
Yes	47.2	26.3	
Do not know/doubtful	24.4	30.4	
No	28.4	43.3	
These are the best years of my life (b,e)			< 0.0005
No	65.1	38.3	
Do not know/doubtful	23.4	34.8	
Yes	11.5	26.9	
I am very satisfied with my life at present (a,d)			< 0.0005
No	27.9	8.1	
Do not know/doubtful	29.1	22.7	
Yes	43.0	69.2	
Total score for quality of life mean (SD)	18.3 (4.5)	21.6 (3.9)	< 0.001

Cronbach's alpha coefficient = 0.86 (*n* = 793), = 0.87 (*n* = 448).

Possible score for quality of life (QoL) range from 8–28, where 28 is the best score for QoL and 8 the worst.

The Mann-Whitney *U*-test was used for the analyses of the quality of life questions and the *t*-test for the total score.

Internal missing among old people receiving help (a) = 12–32, (b) = 39–55.

Internal missing among old people not receiving help (c) = 12–32, (d) = 39–58, (e) = 98–124.

Results

Included in this study were 448 people receiving help and 793 people without help. Seven people did not answer the question about receiving help or care and were therefore excluded. There was a significantly (chi square = 68.773, *df* = 3, *P* < 0.001) higher dropout (42.7%) in the youngest age group (75–79 years) than in the oldest (16.5%)

(90–99 years), and 27.3% in the age group 80–84 and 24.1% in the 85–89 group. There was a higher dropout among men than women, 36.8% compared with 31.2%. Reasons for not participating were, for example, 'too old', 'not feeling well', 'do not have anything to say' or 'do not want to participate'.

Among those receiving help, 79.1% came from the oldest age group (90–99), and 18.5% from the youngest age group (75–79 years); for those without help, 20.0% came from the oldest age group (90–99 years) and 81.4% from the youngest age group. To complete the questionnaire, significantly (chi square = 284.650, $df = 1$, $P < 0.001$) more people receiving help (66.7%) needed help from another person (from relatives in 45.1%, home help service in 12.7%, friends in 3.8%, and district health service in 3.3%) compared with 18.1% people without help (from relatives in 14.6%, friends in 2.8%, district health service in 0.9%, and home help service in 0.5%). There was significantly higher age, more women, more people who were widowed, more children, more people living alone and fewer people who were able to be alone at home among those receiving help (Table 1). In both groups significantly more women than men lived in the city (receiving help; chi square = 8.607, $df = 2$, $P < 0.01$, without help; chi square = 15.056, $df = 2$, $P < 0.05$), had lost their partner (receiving help; chi square = 81.186, $df = 3$, $P < 0.001$, without help; chi square = 150.162, $df = 3$, $P < 0.001$) and lived alone (receiving help; chi square = 76.411, $df = 3$, $P < 0.001$, without help; chi square = 127.927, $df = 3$, $P < 0.001$).

The number of self-reported diseases per person in the group receiving help ranged from none (8.3%) to 14 (0.2%), and among the people without help from none (26.9%) to 10 (0.1%). There were no significant differences in the number of self-reported diseases with regard to gender within the two groups. There was, however, a significantly higher incidence of disease among those receiving help (Table 2). The four most common diseases reported in both groups were musculoskeletal diseases, other circulatory diseases, eye diseases and hypertension, although in a different order in the two groups (Table 2).

The number of symptoms was significantly ($U = 90,366.000$, $Z = -14.423$, $P < 0.0005$) higher among those receiving help (median = 10, $q1/q3 = 6/13$) than among those without help (median = 4, $q1/q3 = 2/8$). It ranged from none (2.7%) to 26 (0.2%) in those receiving help and from none (10.5%) to 26 (0.1%) in those without. There were no significant differences in the number of symptoms with regard to gender within the two groups. In both groups, musculoskeletal pain was most frequent, followed by impaired mobility among those receiving help, whilst

impaired hearing was the second next most common symptom in those without help (Figure 1).

As regards each question on QoL, 63.5% to 74.4% among those receiving help stated that they had 'good' or 'very good' QoL, and 85.3% to 93.8% among those without help (Table 3). There were significant differences in all variables. With regard to gender, there were no significant differences in total QoL among those receiving help, but in the other group significantly ($U = 37,163.500$, $Z = -3.546$, $P < 0.0005$) more women had a lower total QoL score than men.

The linear regression analysis showed depressed mood (little), loneliness (little and much) and abdominal pain (much) to be significantly associated with low QoL in both groups. Among those receiving help, not being able to stay alone at home and fatigue (very much), depressed mood (much and very much) and loneliness (very much) were found to be significantly associated with low QoL and living alone was significantly associated with high QoL. Among those without help, the number of diseases, abdominal pain (little) and sleeping problems (little) was significantly associated with low QoL (Table 4).

Discussion

In this study there were significant differences in terms of higher age, more women, more widows/widowers, more people not able to stay alone at home by themselves and more people living alone among those receiving help. Also, more self-reported diseases and symptoms were found among those receiving help. People receiving help had significantly lower QoL, and predictors of low QoL among those receiving help were living alone, not being able to stay alone at home, and fatigue. However, among those without help, number of diseases and sleeping problems were predictors of low QoL, and in both groups loneliness, depressed mood and abdominal pain predicted low QoL.

These findings were based on a questionnaire, which has implications for internal and external validity. The general response rate was 67%, which is quite good bearing in mind the age of the sample (Polit & Hungler 1999). Interestingly, the response rate was higher among those over 80 years of age (72.3–84.3%) than among the younger older people (75–79 years of age), where the response rate was 57.3%. The reasons given for not responding were mainly related to health. It seems likely that a large proportion of non-respondents were healthy, since the dropouts mainly came from the younger age groups. In other studies there are usually more dropouts in the higher age groups (Grimby *et al.* 1999). Thus, our findings seem likely to represent the situation of older people accurately, especially those 80 years

Table 4 Variables associated with quality of life (linear regression, enter) in respondents with or without help

	With help			Without help		
	B	95% confidence interval	P value	B	95% confidence interval	P value
Age	0.071	−0.001 to 0.143	< 0.054	0.009	−0.063 to 0.081	NS
Women	−0.174	−1.046 to 0.698	NS	−0.208	−0.798 to 0.382	NS
Number of diseases	0.069	−0.116 to 0.255	NS	−0.373	−0.548 to −0.198	< 0.000***
Living alone	1.191	0.223 to 2.160	< 0.016*	−0.076	−0.716 to 0.563	NS
Not able to stay at home alone	−2.027	−3.561 to −0.493	< 0.010*	2.317	−2.073 to 6.707	NS
Abdominal pain (little)	−0.507	−1.485 to 0.472	NS	−0.874	−1.639 to −0.109	< 0.025*
Abdominal pain (much)	−2.080	−3.864 to −0.296	< 0.022*	−3.970	−6.168 to −1.773	< 0.000***
Abdominal pain (very much)	−1.994	−4.268 to 0.279	NS	0.845	−5.365 to 7.054	NS
Fatigue (little)	−0.599	−1.496 to 0.299	NS	−0.379	−1.087 to 0.329	NS
Fatigue (much)	−0.787	−2.019 to 0.445	NS	0.378	−1.264 to 2.020	NS
Fatigue (very much)	−2.840	−4.703 to −0.977	< 0.003**	0.366	−9.192 to 9.924	NS
Sleeping problems (little)	−0.384	−1.206 to 0.437	NS	−0.643	−1.256 to −0.030	< 0.040*
Sleeping problems (much)	−1.072	−2.608 to 0.464	NS	−0.714	−2.254 to 0.825	NS
Sleeping problems (very much)	−1.636	−3.840 to 0.568	NS	−0.999	−3.588 to 1.589	NS
Depressed mood (little)	−2.117	−3.031 to −1.203	< 0.000***	−2.182	−3.019 to −1.346	< 0.000***
Depressed mood (much)	−2.444	−4.357 to −0.530	< 0.012*	−1.669	−5.497 to 2.159	NS
Depressed mood (very much)	−3.160	−5.714 to −0.606	< 0.015*	−4.037	−9.025 to 0.951	NS
Loneliness (little)	−2.210	−3.189 to −1.232	< 0.000***	−2.735	−3.493 to −1.978	< 0.000***
Loneliness (much)	−3.882	−5.420 to −2.343	< 0.000***	−4.548	−6.288 to −2.809	< 0.000***
Loneliness (very much)	−5.247	−6.826 to −3.668	< 0.000***	−2.877	−6.327 to 0.573	NS

Variables of no significant influence and not included in the model were number of symptoms, number of children, civil status, living condition, memory, dizziness, loss of appetite, impaired sight, impaired mobility, musculoskeletal pain, breathlessness, anxiety and nervousness.

*significance = 5%, **significance = 1%, ***significance = 0.1%.

of age or above, whilst younger older people seem to be less well-represented.

Another threat to validity may be that more people had help to respond to the questionnaire from family members or others. This approach can be questioned. We asked respondents if they had had help in filling out the questionnaire and by whom. This made it clear whether or not they had received help, which may otherwise happen in postal questionnaire studies without researchers knowing this. It is not possible to state whether this help distorted the results. It may, however, mean that those likely to have dropped out participated because of the help received. The internal dropout in general was acceptable.

Some questions about QoL had a higher dropout in both groups (Table 3). The total score, however, showed high internal consistency (0.86–0.87) and showed similar individual responses between the items; the internal dropout may thus be of less significance. The assessment of QoL was grounded on eight items based on Life quality Gerontological Centre scale, Lund (Nordbeck 1996). This selection can be questioned. The reason for not taking a full measure was to avoid overburdening older people with a lengthy scale, as this would have had an impact on internal as well as external dropout. Also, it may strengthen the validity of the study that the items reflected overall QoL rather than HRQoL.

Applying HRQoL measures and analysing these in relation to symptoms and restrictions of various kinds can introduce considerable redundancy. The items used seemed to be sensitive in differentiating between the two groups. In general, it seems that the findings may be taken as a fair representation of the situation of older people living at home and receiving help or not for their daily living in Sweden, and in comparable communities and age groups.

The most obvious finding was the significantly lower QoL among those receiving help from others. Approximately 30% answered that they had low or very low QoL, while in the other group approximately 10% reported low or very low QoL in these items. There is a lack of comparable studies, i.e. those comparing older people at home who have help with those without. As expected, people receiving help had more self-reported diseases and more symptoms, which might lead to low QoL. It is surprising, however, that the differences with regard to symptoms, self-reported diseases and QoL were so large, especially as the regression analyses did not show numbers of symptoms and self-reported diseases to be significantly associated with QoL among those receiving help. The large differences in QoL are likely to be explained by the complex of symptoms rather than single symptoms, which marks the transition from living independently to becoming dependent on help. Nilsson *et al.* (2000) found in their study

among older people (85–96 years of age) living at home in Sweden that older people's experiences of feeling old passed through four stages of transition: beginning to feel old, fear of being helpless, recognizing one's former self and feeling different from others. It may well be that those in earlier phases of the transition have a greater negative impact on QoL, i.e. before adjustment to new circumstances has been attained. Further studies are needed about this transition and are important for nursing care so that nursing interventions can be adapted to the needs of older people.

The larger number and degree of various symptoms may explain QoL through the impact of the symptoms themselves as well as through their impact on people's autonomy, as discussed above. The differences in level were particularly high with regard to musculoskeletal pain, impaired mobility, sight, dizziness and fatigue among those receiving help compared with those not, and were in most cases 20–25% higher (Figure 1). These factors may well be part of the reason why they receive help. Steen *et al.* (2001) found mobility and fatigue to be predictors of ADL dependence among 85-year-olds living in the community or in special accommodation. Furthermore, other studies showed comorbidity (Grimby & Svanborg 1997) and multiple health problems, for example fatigue and pain (Michelson *et al.* 2001), to be associated with reduced QoL. The high level of these symptoms is important from a nursing care perspective because of the possibility of addressing them in rehabilitation programmes (Sonn & Hulter Åsberg 1991, Sonn 1996). It is generally recognized that such problems create a vicious circle (Sonn 1996, Steen *et al.* 2001). Musculoskeletal pain and impaired sight, for instance, may lead to fear of moving, which in turn increases stiffness and mobility problems. It is also important to acknowledge that these symptoms do not work in isolation, but rather interact with each other (Jakobsson *et al.* 2003). Thus, systematic assessment of various common symptoms in older people and interventions that address the complexity rather than novel symptoms seem urgent in order to improve the life situation of those living at home and receiving help with daily living.

Although symptoms to a certain degree did determine QoL, it was some specific symptoms and living conditions that predicted low QoL. Thus, it is especially important to focus systematically on these symptoms in nursing care. Variables with the greatest negative impact were loneliness, depressed mood, fatigue and abdominal pain in those receiving help. Thus, psychological components (depressed mood, loneliness) and physical components (fatigue, pain) together explained the low QoL, especially in those receiving help. Abdominal pain was common, which has not

previously been identified as a problem. Fatigue, however, has been reported repeatedly as contributing to low QoL in older people (Steen *et al.* 2001). This calls urgently for in-depth studies of fatigue, and also development of interventions that can minimize it. The strongest factors contributing to low QoL were depression and loneliness, i.e. the psychological aspects of QoL. These symptoms were also predictors of low QoL in those not receiving help, although they were even stronger as predictors of low QoL in those receiving help. Similar findings have been reported in other studies (Grimby & Wiklund 1994, Jensen *et al.* 1994, Lindgren *et al.* 1994, Newsom & Schulz 1996, Fassino *et al.* 2002), either as a predictor of low QoL or in observed and perceived correlation with impaired QoL. Surprisingly, living alone contributed to a better QoL in regression analysis among those receiving help, which resembles the findings of Iliffe *et al.* (1992) that older people over 75 years of age living alone in London had higher satisfaction with life than those living with others. These findings indicate the importance of assessing loneliness and depression when providing home care, and also considering the social aspect of daily living for older people. Our findings also show that, the more restricted a person's ability to manage by themselves, the lower their QoL. Not being able to stay at home alone without someone available to assist predicted low QoL, which is likely to reflect low functional ability. This variable has not to our knowledge been used before. Apart from the fact that it may reflect the person's functional limitations, it may also reflect feelings of restricted autonomy and dependency on others and thus be part of the psychological components contributing to low QoL. It also seems worthwhile to address feelings of having to rely on others in the assessment as well as counselling of older people.

The fact that different variables contributed to low QoL in those receiving help and those not indicates that knowledge obtained from healthy older people about QoL cannot be generalised to those receiving help. Rather, they should be regarded as a different group. The transition from living independently to receiving help from others probably contributes to a change of values and attitudes about what is important in life. From a clinical perspective, this indicates that assessment of various symptoms and their importance for each individual is vital. It is likely that low QoL is the result of a combination of emerging need for help from others and the suffering caused by various symptoms. Clinically, these findings emphasize the need for thorough assessment and monitoring, e.g. by a district nurse, of older people who are living at home and who are restricted in their own resources in handling daily living.

What is already known about this topic

- Older people who are functionally disabled are more likely to receive help to live at home and are at higher risk of lower quality of life.
- With increasing age, the risk of multiple morbidity and symptoms increases.

What this paper adds

- Differences in symptoms and quality of life for older people receiving and not receiving help at home.
- Information about symptoms that contribute to low quality of life among older people.
- Nurses need to take these factors into consideration when providing care.

Conclusions

It seems fair to say that living at home and receiving help does not protect older people from having a low QoL. Considerable differences between those living without help and those with help with respect to most symptoms, not being able to stay at home alone by themselves and to QoL are to be expected. Thus the findings point to the importance of nurses' doing systematic assessment from a broader perspective and interventions especially focusing on symptoms that contribute to a low QoL on older people receiving help from others for their daily living.

Acknowledgements

We are grateful to the participants and to all colleagues in the Department of Nursing, Unit for Caring Sciences, Lund University. We acknowledge the support of the County Council of Kristianstad and the Freemasons of Skåne, Skånska Provinsiallogen. We are also grateful to Ulla Welanders Hansson (Kristianstad) for data collection, Vibeke Horstman (Gerontology Research in Lund) for statistical help and to Jane Mattisson, Blekinge Institute of Technology, and Alan Crozier (Lund) for revising the English.

References

Al-Windi A., Elmfeldt D., Tibblin G. & Svärdsudd K. (1999) The influence of sociodemographic characteristics on well-being and symptoms in a Swedish community. *Scandinavian Journal of Primary Health Care* 17, 201–209.

- Bowling A. & Browne P. (1991) Social networks, health, and emotional well-being among the oldest old in London. *Journal of Gerontology: Social Sciences* 46(1), 20–32.
- Browne J.P., O'Boyle C.A., McGee H.M., Joyce C.R.B., McDonald N.J., O'Malley K. & Hiltbrunner B. (1994) Individual quality of life in the healthy elderly. *Quality of Life Research* 3, 235–244.
- Campbell A.J., Busby W.J., Robertson M.C., Lum C.L., Langlois J.A. & Morgan F.C. (1994) Disease, impairment, disability and social handicap: a community based study of people aged 70 years and over. *Disability and Rehabilitation* 16(2), 72–79.
- Cohen L. & Manion L. (1989) *Research Methods in Education*. Routledge, London.
- Criddle A.R. & Flinder L. (2001) Helping older people to remain in their own homes. *The Medical Journal of Australia* 174, 266–267.
- Ellefson B. (2002) Dependency as disadvantage – patients' experiences. *Scandinavian Journal of Caring Sciences* 16, 157–164.
- Elmståhl S., Sommer M. & Hagberg B. (1996) A 3-year follow-up of stroke patients: relationships between activities of daily living and personality characteristics. *Archives of Gerontology and Geriatrics* 22, 233–244.
- Fassino S., Leombruni P., Abbate Daga G., Brustolin A., Giacomo Rovera G. & Fabris F. (2002) Quality of life in dependent older adults living at home. *Archives of Gerontology and Geriatrics* 35, 9–20.
- Fernández-Ballesteros R. (2002) Social Support and Quality of Life Among Older People in Spain. *Journal of Social Issues* 58(4), 645–659.
- Frederiks C.M., te Wierik M.J., Visser A. & Sturmans F. (1990) The functional status and utilization of care of elderly people living at home. *Journal of Community Health* 15(5), 307–317.
- Grimby A. & Svanborg A. (1997) Morbidity and health-related quality of life among ambulant elderly citizens. *Aging Clinical and Experimental Research* 9(5), 356–364.
- Grimby A. & Wiklund I. (1994) Health-Related Quality of Life in Old Age. A Study among 76-Year-Old Swedish Urban Citizens. *Scandinavian Journal of Social Medicine* 22(1), 7–14.
- Grimby C., Fastbom J., Forsell Y., Thorslund M., Claesson C.B. & Winblad B. (1999) Musculoskeletal pain and analgesic therapy in a very old population. *Archives of Gerontology and Geriatrics* 29, 29–43.
- Hagberg M., Hagberg B. & Saveman B.-I. (2002) The significance of personality factors for various dimensions of life quality among older people. *Aging & Mental Health* 6(2), 178–185.
- Hellström Y. & Hallberg I. (2001) Perspectives of elderly people receiving home help on health, care and quality of life. *Health and Social Care in the Community* 9(2), 61–71.
- Iliffe S., See Tai S., Haines A., Gullivan S., Goldenberg E., Booroff A. & Morgan P. (1992) Are elderly people living alone at risk group? *British Medical Journal* 305, 1001–1004.
- Jacobsson C., Axelsson K., Osterlind P. & Norberg A. (2000) How people with stroke and healthy older people experience the eating process. *Journal of Clinical Nursing* 9(2), 255–264.
- Jacobsson U., Klevegård R., Westergren A. & Hallberg I. (2003) Old people in pain: a comparative study. *Journal of Pain and Symptom Management* 26(1), 625–636.
- Jensen E., Dehlin O., Hagberg B., Samuelsson G. & Svensson T. (1994) Depressive symptoms in a 80-year-old population in

- relation to medical, psychologic, and sociologic factors. *Nordic Journal of Psychiatry* 48(5), 349–354.
- Jorm A.F., Henderson S., Scott R., Mackinnon A.J., Korten A.E. & Chistenen H. (1993) The disabled elderly living in the community: care received from family and formal services. *The Medical Journal of Australia* 158(15), 383–387.
- Kinsella K. & Velkoff V.A. (2001) *An Aging World: 2001*. U.S. Census Bureau, Washington.
- Lawton M.P. (1975) The Philadelphia Geriatric Centre Morale Scale: a revision. *Journal of Gerontology* 30(1), 85–89.
- Lawton M.P. (1991) *A Multidimensional View of Quality of Life in Frail Elders*. Academic Press, San Diego, New York, Boston, London, Sydney, Tokyo, Toronto.
- Lawton M.P., Moss M. & Duhamel L.M. (1995) The quality of daily life among elderly care receivers. *The Journal of Applied Gerontology* 14(2), 150–171.
- Lindgren A.-M., Svärdsudd K. & Tibblin G. (1994) Factors related to perceived health among elderly people: the Albertina Project. *Age and Ageing* 23, 328–333.
- Lindgren A.-M., Svärdsudd K. & Tibblin G. (1998) Are health surveys among elderly people worthwhile? The Albertina Project. *Scandinavian Journal of Primary Health Care* 16, 101–106.
- Melzer D., McWilliams B., Brayne C., Johnson T. & Bond J. (1999) Profile of disability in elderly people: estimates from a longitudinal population study. *British Medical Journal* 318(7191), 1108–1111.
- Michelson H., Bolund C. & Brandberg Y. (2001) Multiple chronic health problems are negatively associated with health related quality of life (HRQoL) irrespective of age. *Quality of Life Research* 9, 1093–1104.
- National Swedish Board of Health & Welfare (2000) *Service and Care to Elderly Persons 1999 (Vård och omsorg om äldre 1999)* (in Swedish). The National Board of Health and Welfare (Socialstyrelsen), Stockholm.
- National Swedish Board of Health & Welfare (2003) *Care and Services to Elderly Persons 2002. Äldre - vård och omsorg år 2002* (in Swedish). Socialstyrelsen, The National Board of Health and Welfare, Stockholm.
- Neugarten B.L., Havighurst R.J. & Tobin S.S. (1961) The measurement of life satisfaction. *Journal of Gerontology* 16, 134–143.
- Newsom J.T. & Schulz R. (1996) Social Support as a Mediator in Relation Between Functional Status and Quality of Life in Older Adults. *Psychology & Aging* 11(1), 34–44.
- Newsom J.T. & Schulz R. (1998) Caregiving from the recipient's perspective: negative reactions to being helped. *Health Psychology* 17(2), 172–181.
- Nilsson M., Sarvimäki A. & Ekman S.-L. (2000) Feeling old: being in a phase of transition in later life. *Nursing Inquiry* 7, 41–49.
- Nordbeck B. (1996) Quality of Life and Life Satisfaction among centenarians. *Gerontology Research Centre Lund* 21, 1–16.
- Penninx B.W.J.H., Leveille S., Ferrucci L., van Eijk J.Th.M. & Guralnik J.M. (1999) Exploring the Effect of Depression on Physical Disability: Longitudinal Evidence from the Established Populations for Epidemiologic Studies of the Elderly. *American Journal of Public Health* 89(9), 1346–1352.
- Philip I. (1996) Measuring and promoting quality of life in health care for elderly people. *Australian Journal on Ageing* 15(3), 17–20.
- Polit D.F. & Hungler B.P. (1999) *Nursing Research: Principles and Methods*. J.P. Lippincott Company, Toronto.
- Rubenowitz S. (1980) *Metodutveckling för kartläggning av psykosociala faktorer i samband med den regionala utvecklingsplaneringen* (in Swedish). Statens psykologisk-pedagogiska bibliotek, Göteborg, 34 pp.
- Sonn U. (1996) Longitudinal studies of dependence in daily life activities among elderly persons. *Scandinavian Journal of Rehabilitation Medicine* 28(Suppl. 34), 2–35.
- Sonn U. & Hulter Åsberg K. (1991) Assessment of activities of daily living in the elderly: a study of a population of 76-year-olds in Gothenburg, Sweden. *Scandinavian Journal of Rehabilitation Medicine* 23, 193–202.
- Statistics Sweden (SCB) (2002) *Statistisk årsbok (in Swedish)*. Statistiska Centralbyrån, Stockholm.
- Steen G., Sonn U., Hanson A.B. & Steen B. (2001) Cognitive function and functional ability. A cross-sectional and longitudinal study at ages 85 and 95 in a non-demented population. *Aging Clinical and Experimental Research* 13(2), 68–77.
- Swedish Institute (1999) *The Care of the Elderly in Sweden*. Fact Sheets on Sweden, The Swedish Institute, Stockholm.
- WHOQOL (1998) Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. *Psychological Medicine* 28, 551–558.